The right to genetic ignorance

The age of genomic medicine is dawning. Whole-genome sequencing is starting to transform the diagnosis of rare inherited diseases, and within a few decades it could be a routine part of medical care.

The intentions are laudable, but routine disclosure may not always be welcome. Imagine that you are seeking the cause of a mysterious condition that has brought your child to death's door. Do you want to worry about other potential problems that may not pose a risk until later in life? And if there are unwelcome surprises, you and other relatives may carry the same defects. Do you want to be burdened with that knowledge?

Read the full, original story here: The right to genetic ignorance

Additional Resources:

- "Do You Have a Right to Genetic Ignorance? Bioethicists say yes, but it's not a good idea." reason.com
  In this article, the author highlights the difficult position of a physician, who is professionally-bound to offer potentially lifesaving information.
- "Recommendations for returning genomic incidental findings? We need to talk!" Nature
  In May of 2013, a panel of researchers responded to the American College of Medical Genetics and Genomics' guidelines for whole-genome and whole-exome sequencing. They concluded on a cautionary note: "The genetics community needs to ensure active debate of different uses of genome sequencing, different approaches to ensuring and supporting patient choice, and the ethical frameworks and evidence base needed to justify those uses. … As an extraordinarily powerful and innovative technology, genome sequencing has the potential for both benefit and harm to patients."